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Experimental Selves: Experiences, Expectations and Discourses of Cancer Research, 1960 - 2010

You are being invited to take part in a research study. This is an oral history study, which means that people who take part will be interviewed and the interviews will be recorded.

Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The research is part of a PhD project in the History of Medicine.

The study will consider what it was like to take part in a clinical trial for lymphoma research. Up to now, the history of cancer research does not include the stories of research subjects. This project will try to put the stories of a group of research subjects back into medical history. It is my belief that without the individual stories the history is incomplete.

The research project will consider issues such as:

1. How did people feel about taking part in a clinical trial? What were their reasons for taking part? Who or what influenced the decision to take part?
2. What did people understand about clinical trials? How did they find out about them?
3. What do people remember about being in a trial? How do people feel now about their participation in a trial? How did it affect their lives from that point onwards?

This is by no means a complete list. The interviews will raise other questions based on individual experience and memory.

Why have I been invited to participate?

You have been invited to participate because you, or someone close to you, have been involved in a clinical trial for lymphoma patients in Britain in the recent past.

Do I have to take part?

No, you do not have to take part. This information is to help you decide.

If you decide to take part you can change your mind and withdraw at any time without giving a reason.

What will happen to me if I take part?

You will be interviewed by a PhD research student who has experience of working with people with lymphoma. The interview will take between 45 minutes and 2 hours. The length of the interview will depend on the individual, but the average length of interview is one hour.

If you agree, the interviews will take place in your own home. It might be possible to interview you somewhere else if you like, provided the venue is quiet and you feel comfortable there.

The interview will be recorded using a recording device that will be placed next to you.

You will be free to talk about whatever parts of your experience are most relevant to you. The researcher will be interested in particular topics, but the content of the interview will be very flexible. Example subject areas might include:

- your life before and after your diagnosis
- the trial you were in and what it involved
- what you understood about the trial and what your expectations were.

You will be asked to sign a consent form. This is to indicate that you have read this information and that you understand it.

What will happen to the recording?

The information you provide will form part of a PhD thesis which will be completed in 2015.

You will receive a transcript of the interview. A transcript is a written version of the recorded conversation. You will have the opportunity to check them for accuracy and make minor corrections. You will be given a copy of the transcribed and corrected interview. You can use your copy for any desired purpose.

The transcribed and corrected interview may be used by Oxford Brookes University in article and / or in book form. The researcher may use extracts from your interview in presentations at conferences or seminars.

At the end of the research project, you will be asked whether or not you would like your recording to be donated to the permanent collection of the Sound Archive of the Wellcome Library in London. The Wellcome Library specialises in medical research and the history of medicine. Donation of your recording would mean it is available to other people interested in medical research who might wish to use your story in their research. You will be given more information about the Wellcome archive and their access policies at the time. If you would like more information about this now, please ask.

What are the possible risks of taking part?

Sometimes talking about the experience of lymphoma can bring back upsetting memories and feelings.

You can suspend the interview at any time if you want to.

If you would like to talk to someone about how you feel afterwards, you can telephone the Lymphoma Association Helpline. Their telephone number is 0808 808 5555, and they are open from 9 – 6pm, Monday – Friday. You can also contact them by email or online at www.lymphomas.org.uk.

Because you may talk about other individuals, such as your doctor, they will need to be protected from claims that might be damaging to them. Where there is any possibility of defamation or libel, individual names will be removed from the recording and the transcript.

What are the possible benefits of taking part?

Talking about your experience for the history books should be an enjoyable experience.

People who take part in trials make a contribution to medical history, but their stories are seldom told. You will be taking part in a study that will fill a gap in medical history. Your story will put the people back into the statistics and give us a better understanding of what it means to be part of a clinical trial.

Will what I say in this study be kept confidential?

This research project is intended to put individual stories back into medical history. For that reason, your story will be used in material that is made available to the public.

You can use your own name in the recordings if you wish. Or, if you prefer, you can opt to be anonymous or to use a false name (pseudonym) instead of your own. Your identity may still be apparent even if you use a pseudonym. For example, if you refer to a specific place or event it might be possible for a listener to identify who you are.

Recorded extracts of your voice might be used at academic conferences and the Lymphoma Association conference. Your first name or a pseudonym might be used to introduce extracts from your story if you agree.

For legal reasons, your real name and details will be recorded to give copyright to Oxford Brookes University (see below). These details will be on a separate form that is kept confidential. Information generated by the study must be retained in accordance with the University's policy on Academic Integrity. This means that it must be kept securely in paper or electronic form for a period of ten years after the project has been completed.

Confidentiality can only be preserved within the limits of the law.

What does 'assigning copyright' mean?

Under the law, you own the copyright of your own recorded voice. This means that no one can use your recording in writing or in public without your permission. For the recording to be used in producing published research, or in any way that is publicly accessible, the University needs your written permission. It is easier to get your permission now, than to contact you on each occasion that the material might be used in the future. Please ask if you would any further information about copyright.

What should I do if I want to take part?

If you are happy to take part, please sign the accompanying reply slip and return it to me by post, or email me at: catriona.gilmour.hamilton-2012@brookes.ac.uk

What will happen to the results of the research study?

Information from participant interviews will form the basis of a PhD dissertation. This will be available to all online via Oxford Brookes University from 2015. You will be notified of the date of publication. The information will also be used to write academic articles and a book chapter.

Who is organising and funding the research?

This research is being organised and conducted by Catriona Gilmour Hamilton who is a PhD student at the Centre for Health, Medicine and Society, Department of History, Philosophy & Religion at Oxford Brookes University. The research is funded as part of a grant from the Wellcome Trust. The grant is funding a group of research projects on the subject of experiences of medical research.

Who has reviewed the study?

This research has been approved by the University Research Ethics Committee, Oxford Brookes University.

Contact for Further Information

If you have any questions you can contact Catriona at catriona.gilmour.hamilton-2012@brookes.ac.uk or Dr Viviane Quirke, Senior Lecturer in Modern History and History of Medicine at vquirke@brookes.ac.uk. If you have any concerns about the way in which the study has been conducted, you can contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk. Thank you for taking the time to read this information sheet.

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PARTICIPANT REPLY SLIP

I would like to participate in the above oral history research project. I understand that the aims and purposes of the study will be explained to me prior to the interview at which point I will be asked to sign a consent form.

I understand that the researcher will contact me to discuss the arrangement of an interview.

Name:

Address:

Email address:

Telephone number:

Signed:

Please return this reply slip by post to:

Catriona Gilmour Hamilton
C/o Dr Viviane Quirke
Centre for Health Medicine and Society
Tonge Building
Oxford Brookes University
Gypsy Lane
Oxford
OX3 0BP

or by email to:

catriona.gilmour.hamilton-2012@brookes.ac.uk